Navigating Impasses in Bioethics: Rethinking Ill/Health

Friday 4 December 2015
St Edmund's College, Cambridge

SPEAKERS AND PAPERS

The human right to health and the conflation problem

Human Rights advocates often use loose, inflated and thus underspecified terminologies when addressing the content of their claims. One such loose term is 'well-being', as currently employed as a definition for the right to health. What I have called the 'well-being conception of health' conflates both basic and non-basic health needs. This distinction is key as these different types of health needs are underpinned by different moral claims. I will call this the conflation problem, and I will also explore other loose terminologies as the legal parlance that end-up conflating different moral values.

Thana Campos joined the VHI in 2014. She currently is Adjunct Professor at the Faculty of Law of the University of Ottawa, Canada. Thana holds a DPhil in Law (Jurisprudence) from the University of Oxford. She is also the co-chair of the ASAP-Brazil, where she directs the Right to Health Research Group. Her book, *Transnational Corporations and Human Rights – Pharmaceutical Corporations as a Case Study* (in Portuguese, Ed. Forum, 2012) discusses the moral justification of medical patents and its reasonable limitations in relation to one specific public health problem that she calls the 'Global Health Crisis', which is exacerbated by the paucity of medical research into 'neglected diseases'.

Health as vulnerability; interdependence and relationality

The WHO defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." This description of health is woefully inadequate. It is individualistic, seeing health as residing in individual bodies and not recognizing that health is inherently relational and communal. It perpetuates the norm of the able bodied, invulnerable and independent person and fails to recognize our universal vulnerability; the "leaky" natures of our bodies and our profound interdependence. This chapter will promote an image of health which is relational, vulnerable and interdependent.

Jonathan Herring is a Fellow in Law at Exeter College, Oxford University and Professor of Law at the Law Faculty, Oxford University. He has written on family law, medical law, criminal law and legal issues surrounding care and old age. His books include: *Medical Law and Ethics* (OUP 2016); *Family Law* (Pearson, 2015); *Caring and the Law* (2014); *Criminal Law* (Oxford University Press 2014); *European Human Rights and Family Law* (Hart, 2010) (with Shazia Choudhry); *Older People in Law and Society* (OUP, 2009); and *The Woman Who Tickled Too Much* (Pearson, 2009).

Jettisoning 'the sanctity of life principle'

The aim of this paper is to explore an important element of medical ethics and law which is widely acknowledged but about which people are often confused. This element is perhaps most frequently referred to as 'the principle of the sanctity of life' and it is often assumed that this language has a religious provenance. However, the phrase is neither rooted in the traditions it purports to represent nor is it used consistently in contemporary discourse. There have been recent attempts to rescue this terminology from confusion and inconsistency but there is a strong argument for jettisoning the language altogether. This paper traces the origin of the current use of the phrase 'the sanctity of life'. It argues that the ethical issues of killing and sustaining life in a medical context are best understood not in relation to this language but in relation the concept of virtue, in particular the virtue of 'respect for human life'. To understand this as a virtue, in the Aristotelian sense, will involve both recognising an aspect of respect that is a mean between extremes, and also recognising that the virtue of respect excludes certain kinds of action as inherently unvirtuous. This represents well the Hippocratic tradition of medical ethics, the virtue ethics tradition, the tradition of natural law, and the basis of the common law on killing and sustaining life. The idea that 'respect for human life' is a virtue has real explanatory power and has much to recommend it.

David Albert Jones has been Director of the Anscombe Bioethics Centre since July 2010, and is also a Research Fellow in Bioethics at Blackfriars Hall, Oxford. After reading Natural Sciences and Philosophy at Cambridge and Theology at Oxford, Professor Jones was made director of the Linacre Centre for Healthcare Ethics in 2001, and was subsequently appointed Professor of Bioethics and Director of the Centre for Bioethics and Emerging Technologies, at St Mary's University, Twickenham, where he remains a Visiting Professor. Professor Jones' doctorate was published in 2007 as *Approaching the End* (OUP). His previous book *The Soul of the Embryo* (Continuum) was short-listed for the Michael Ramsey Prize in 2007. He is also Vice-chair of the Ministry of Defence Research Ethics Committee, and external examiner for the Diploma on Medicine and Philosophy run by the Society of Apothecaries.

Health or illness, person or patient: Blurring the lines in the development of pre-symptomatic biomarkers for dementia

In this paper I examine how the concept of mental health over the life-course is being reshaped through the development of pre-symptomatic biomarkers in dementia research. Pre-symptomatic identification and intervention, particularly around Alzheimer's disease (AD), is becoming an increasingly mainstream scientific and political priority across Western Europe and North America. Such research is invested with the hope for future disease modifying treatments which can address the personal, familial, societal and economic impact of this progressive neurodegenerative disease which sits on the boundaries between neurology, gerontology and old age psychiatry. The process of biomarker research requires large scale data linkage across multiple forms of human data such as health records and biological samples from currently healthy research participants. Population level, epidemiological analysis, it is hoped, will enable the identification of lifestyle, behavioural, *environmental and biological factors which may indicate increased risk or early disease onset. This process challenges the boundaries between biological and clinical research, at what point is a person defined as healthy and what constitutes illness? Is illness defined as the subjective experience of physical and cognitive symptoms or the objective validation of the presence of organic disease activity? Taking an anthropological approach I examine how the blurring lines between health and illness are reflected in the slippage of the word 'patient' into scientific discussions around the development of research with healthy participants. This discussion reflects the continuing debate around the biomedicalisation of mental health and later life, and explores the bioethical questions generated by this emerging field of research.*

Sally Atkinson is an early career researcher in the social sciences. In 2015 she joined the Ethical, Social and Legal Implications (ELSI) work package of the Dementia Platform UK, based at the Institute of Public Health at the University of Cambridge. Previously she was based at the University of Durham, where she completed a doctorate on the emergence of the dementia research infrastructure in the UK. Sally's background is in medical and social anthropology. Her previous work has looked at mental health over the life course, the development of new biotechnologies and scientific infrastructures, the role of public patient involvement in science, and the social impact of chronic neurodegenerative diseases.

Medicalization of health and shared responsibility

Public, occupational and environmental health are relatively novel disciplines compared to the ancient history of medicine. Their development, together with a more insightful knowledge of the human phisiopathology have progressively expanded the field of investigation of medicine to environmental, behavioural and genetic factors that favour the development of certain medical conditions. As a results we have developed different strategies to monitor health and prevent diseases intervening in anticipation of disease themselves when patients are healthy or in a grey area of increased risk. New developments related to genomics and distributed point of care technologies will exacerbate a process of medicalization of health. This process is profoundly re-shaping how medicine interact with general population, states and policy makers and has implications on healthcare system design and individual health choices.

Gianmarco Contino Gianmarco Contino is a Clinical Scientist and Surgeon and Associate Faculty Member at the MRC Hutchison Cancer Unit, University of Cambridge, where he pursues translational projects of Next Generation Sequencing on Oesophageal Cancer. He earned his degree in Medicine and Surgery at the University of Rome Tor Vergata with an experimental thesis in Genetics. He then completed his residency in General Surgery and Surgical Oncology and a PhD program in Translational Medicine at the European Institute of Oncology in Milan. He conducted his research focusing on Pancreatic Cancer at the MGH Cancer Center/Harvard Medical School. Gianmarco is an Honorary Lecturer in the department of Surgery and Cancer at Imperial College of London. He is also an editorial writer on medical and bioethical issues for the Huffington Post.

Conscientious Objection: Understanding the Right of Conscience in Health and Health Care Practice

In situations of moral gravitas, health care professionals are largely protected in the Western world to invoke their right to conscientiously object to providing care that conflicts with their personal, moral and religious beliefs. However, making a conscientious objection needs to be predicated by an understanding of conscience, and knowledge of conscience is notably absent in definition as well as discourse surrounding conscientious objection in health care practice. Moreover, current definitions of health do not place emphasis on the ethical well-being of patients as well as care providers. Exploring health as an ethical condition of wellness in light of conscientious health care provision will be addressed in my paper. I will also discuss how a distance from conscience in conscientious objection could compromise a health care professional's right to conscientious objection, if the fundamental, human right to conscience is not protected in the first place, supported by a focus on the importance of health as a state of ethical well-being.

Christina Lamb, Christina is a doctoral candidate in the Arthur Labatt Family School of Nursing at Western University, London Ontario. Her doctoral research is titled: "Exploring the Lived Experience of Conscientious Objection for Registered Nurses in Ontario". Christina is a Registered Nurse and currently the Nursing Practice Leader for Palliative Care at Bruyere Health Care Organization in Ottawa, Ontario, Canada. Her research interests are in Bioethics, Nursing Ethics, Philosophy of Nursing and Global Health. Having taught undergraduate and graduate courses in Bioethics and Nursing at St. Paul's University and the University of Ottawa, Christina has also been involved in a Canadian International Development Agency's funded project to re-structure the Maternal, Newborn and Child Health Care in Rwanda, servicing the project as a lead in its cross-cutting theme of Ethics. Christina's doctoral specialty is in education, and she is committed to further developing and sustaining Ethics Education for health care professionals as her program of research on completion of her PhD studies.

Disabled, Different, or Both? Health and Neurodiversity

This paper aims to explore the connection between health and developmental disorders, particularly in regard to the notion of 'neurodiversity', which considers high-functioning autism not a lifelong disability but a neurological form within a diversity of human minds. In recent years autistic activist movements have called for a more positive, humanising, identity-first language when describing this condition, rejecting negative language such as 'disorder', 'deficit' and 'impairment', and instead describing autism as a way of being, part of one's personal identity, which doesn't always need to be cured. Is a different form of neurodevelopment necessarily a degenerate one? Is well-being mostly affected by disability itself or by its being classified as abnormality? Drawing on philosophical insights, as well as autism research papers and popular science, I explore advantages and disadvantages of these classifications and the connections between health, autism, personhood and disability.

Lidia Ripamonti is a Research Associate at the Von Hugel Institute, St Edmund's College, Cambridge. She studied philosophy at the Universities of Milan, Freiburg in Breisgau, and Dresden and she holds a PhD from Anglia Ruskin University. Her doctoral thesis discusses Edith Stein's critique of Martin Heidegger, and focuses particularly on the understanding of the human person; most of her research work was carried out while she was an assistant lecturer in philosophy of religion at the University of Dresden, working at the intersection between phenomenology and philosophical anthropology. Lidia has taught and published on intersubjectivity, empathy, personhood, end-of-life, and philosophy of dialogue.

Defining the Relationship between Health and Well-being in Bioethics

Doctors and psychologists often use 'well-being' and 'quality of life' interchangeably, with quality of health overdetermining both. Insights from virtue ethics and St. Thomas Aquinas challenge this. Well-being has a primary 'eudaimonic' dimension, and an accompanying 'subjective' dimension. The 'eudaimonic' consists in a virtuous way of life in which our affective, cognitive, and other capacities are developed in pursuit of worthwhile aims. The 'subjective' consists in attaining and enjoying the goods necessary and fitting to a full human life. Does health - extended to include mental and physical health - account for the 'eudaimonic'? The result would problematically collapse ethics into medicine, and well-being into health. Rather, it is argued that health is a 'subjective' and not a 'eudaimonic' good, and that to a significant degree eudaimonic well-being can persist amid ill-health. Attending to the eudaimonic dimension helps us to overcome characteristic gaps in 'quality of life' discourse.

David Elliot is Research Associate in Theological Ethics at Cambridge University; a position he took up after completing his Ph.D. in Moral Theology in August 2014 at the University of Notre Dame. His dissertation sought to demonstrate how the Theological Virtue of Hope contributes to human happiness and the common good. His primary areas of research are theological hope, virtue ethics, St. Thomas Aquinas, the art of dying, end-of-life issues, and the beatitudes. Recently his research on virtue and happiness was awarded the Essay and Book Prize from the Character Project of the Templeton Foundation for contribution to the study of character. He is currently finishing his first book, *Hope and Christian Ethics*, which is due out next year with Cambridge University Press.

Meaning in Madness?: Theological and Personal Reflections on Mental Illness

Mental illness has been interpreted in different ways through history. Its symptoms have variously been considered a gift signifying the favour of the gods or alternatively a curse indicating the possession of demons. More recently the contrasting views have been between social interpretations involving child abuse, poverty, divorce and other family disruptions and the paradigms of brain science involving genetics, neurology, pharmacology and neuro-imaging techniques. Despite a perennial interest in "miraculous healings", Christians have tended to shy away from mental illness at least at a congregational level preferring to "leave it to the professionals". However it has been claimed that "In many ways, there is no more important disorder for Christians to study and respond to than mental illness" and if this is so then we have a duty to grapple with the issue

theologically and then pastorally. John Foskett, chaplain at the Bethlem Royal and Maudsley Hospitals believes that "'Madness' is an important matter. To understand it one has, incarnate like, to enter into it- into one's own and other people's madness. It is my experience and conviction that there is meaning to be found there." This paper will explore some of the possible meanings of the experience of mental illness through the lenses of Scripture, theological reflection and the poetry of the Jesuit priest G M Hopkins.

Trevor Stammers has been Programme Director for Bioethics and Medical Law at St Mary's University, Twickenham, London, since 2010. He also teaches bioethics, philosophy of health and issues in science and religion in the BA Philosophy programme. He is a writer and occasional broadcaster on bioethical issues and was previously in clinical practice for over thirty years. Trevor was Chair of the Christian Medical Fellowship from 2007 to June 2009. He is the Editor of *The New Bioethics*, an international, multidisciplinary journal of technology and the body linked with the Centre for Bioethics and Emerging Technologies at St Mary's University.
